



Adult Informal Caregivers Reporting Financial Burden In Hawaii, Kansas, And Washington: Results From The 2007 Behavioral Risk Factor Surveillance System

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Abstract

Given the unpaid nature of the work, informal caregiving can create a financial burden for caregivers. Little has been done to identify specific predictors of experiencing financial burden. This study investigated demographic and health factors comparing caregivers who reported having or not having financial burden. Data are derived from adult caregivers (N = 3,317) as part of the 2007 Behavioral Risk Factor Surveillance System in Hawaii, Kansas, and Washington. The adjusted odds ratios for reporting a financial burden were estimated for demographic and other risk factors. Caregivers who reported a financial burden were younger, had lower incomes, were more likely to be current smokers, have had a stroke, and rate their health as fair or poor compared to caregivers who did not report a financial burden. Caregivers who were younger (ages 18-34), resided with care recipients, spent 20-39 hours per week providing care, and reported having a disability were at a statistically significantly higher odds of reporting a financial burden. Given the current economic difficulties faced by many Americans, further insights into the perceived financial burdens experienced by informal caregivers as well as linkages to policy and programs designed to support caregivers are critical for public health professionals to address the expanding needs in states and communities.

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Abstract

Background: Given the unpaid nature of the work, informal caregiving can create a financial burden for caregivers. Little has been done to identify specific predictors of experiencing financial burden. This study investigated demographic and health factors comparing caregivers who reported having or not having financial burden.

Methods: Data are derived from adult caregivers (N = 3,317) as part of the 2007 Behavioral Risk Factor Surveillance System in Hawaii, Kansas, and Washington. The adjusted odds ratios for reporting a financial burden were estimated for demographic and other risk factors.

Results: Caregivers who reported a financial burden were younger, had lower incomes, were more likely to be current smokers, have had a stroke, and rate their health as fair or poor compared to caregivers who did not report a financial burden. Caregivers who were younger (ages 18-34), resided with care recipients, spent 20-39 hours per week providing care, and reported having a disability were at a statistically significantly higher odds of reporting a financial burden.

Conclusions/Implications: Given the current economic difficulties faced by many Americans, further insights into the perceived financial burdens experienced by informal caregivers as well as linkages to policy and programs designed to support caregivers are critical for public health professionals to address the expanding needs in states and communities.

Keywords: Risk factors; Health behaviors; Care recipients; Disability; Stressors

Caregivers in the United States provide many hours of care and many types of care to individuals with disability

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or long-term illnesses and individuals who are aging. The importance of addressing the needs of caregivers as a public health issue is apparent given the size of the population and the associated economic impact [1]. For example, in 2004, it was estimated that annually 44.4 million caregivers provided over \$200 billion in unpaid services to family and friends of varied ages and levels of disability [2]. Caregivers play a critical role for people with disabilities and older adults remaining in the community [3]. Talley and Crews [1] recognized caregiver issues as an important public health concern, and called upon the scientific community to begin to understand the needs of caregivers and implement strategies to address those needs. The World Health Organization (WHO) published its International

Classification of Functioning, Health, and Disability (ICF) in 2001 in which it distanced itself from the definition of disability resulting from disease, to instead promote a vision of disability with participation as the ultimate goal; which seeks to encourage inclusion of persons with disabilities into society [4]. In the ICF's conceptual model of disability, the area of environmental factors, which includes caregivers, is identified as a crucial element that may enable or hinder participation [5]. This model suggests that challenges faced by caregivers that negatively impact their ability to provide care require attention if the goal of enhanced participation by care recipients is to be attained.

There are 2 types of caregivers: informal caregivers and paid caregivers. Paid caregivers are those who have been trained to provide care and are employed to do so. Informal caregivers are family members or friends who provide assistance to children or adults with disabilities or other needs. Informal caregivers may not have received formal training for care giving. Informal caregivers are an important part of the health and social systems in the United States [1,6]. It is estimated that among persons with disabilities who use a caregiver, only 9% reported receiving services from a paid caregiver [7].

Navaie-Waliser and colleagues described the increasing difficulty that informal caregivers may face while seeking supplemental aid through Medicare due to changing policies and limited eligibility [8]. Some of the financial consequences of providing informal care include disruptions in regular employment, having to take time off from work, interfering with work schedules, forgoing promotions or training opportunities, or having to leave employment [2]. MetLife Mature Market Institute reported that caregivers who provide intense personal care can lose over \$650,000 in wages, pensions, and Social Security over their lifetime, a value estimated from total wage wealth at the time of retirement and pension and Social Security benefits over the retirement years [9].

Although caregivers generally report that they would not change their role, numerous studies document that some caregivers experience physical, mental, social, and financial stresses that negatively impact their physical and mental health [3,10-15]. Additionally, caregivers report a variety of burdens or strains associated with providing care, which are varied and differ by type of care provided; providing care has been shown to affect family and social relationships, availability of leisure time, and employment and finances [16]. One study found that reporting financial stress increased the likelihood by as much as nine percentage points of reporting high caregiver stress, which in turn was a significant predictor of care recipient entry into nursing homes [17].

Given the unpaid nature of the work, informal caregiving can create a financial burden for caregivers. However, to our knowledge, specific predictors of experiencing financial burden have yet to be documented. By knowing the demographics of those who experience financial burden, and

identifying predictors of financial burden, more specific and effective interventions can be targeted to alleviate financial burden among caregivers. We used information from the 2007 Behavioral Risk Factor Surveillance System from Hawaii, Kansas, and Washington to assess how common financial burden is among informal caregivers and to investigate the demographic and health factors associated with those caregivers reporting a financial burden. The ultimate objective of this study is to identify intervention areas that can improve health and reduce disparities among caregivers who experience financial burden.

Methods

Data for this study were from the 2007 Behavioral Risk Factor Surveillance System (BRFSS). This annual telephone survey collects data from randomly chosen non-institutionalized adults age 18 and over in all U.S. states and territories. The BRFSS consists of a core section of questions administered in all states as well as separate modules that states may select [18,19]. In 2007, the Caregiver module was administered in 3 states: Hawaii, Kansas, and Washington [20]. A total of 40,979 respondents participated in the BRFSS in the 3 states in 2007.

The caregiver module included a screening question and nine items related to caregiving based on a set of questions developed and tested in North Carolina in 2005 [20,21]. Respondents were classified as informal caregivers if they said "yes" when asked, "People may provide regular care to a family member or friend with a long-term illness or disability. In the past 30 days have you provided any such care?" Respondents who said "no" or "do not know" in response to this question, respondents who reported the care recipient had died within the past 30 days, or respondents who refused to answer the caregiver screening question were excluded from further analyses. Respondents who were classified as informal caregivers were then asked to answer the Caregiver module of questions about the single care recipient for whom they provided the most care.

The outcome of interest, whether respondents experienced financial burden related to caregiving, was determined based on the question, "I am going to read a list of difficulties you may have faced as a caregiver. Please indicate which TWO of the following is the greatest difficulty you have faced in your caregiving." Answer choices were: caregiving creates a financial burden; caregiving doesn't leave enough time for yourself; caregiving doesn't leave enough time for your family; caregiving interferes with your work; caregiving creates or aggravates health problems; caregiving affects your family relationships; caregiving creates stress; another difficulty; or no difficulties. If respondents chose "caregiving creates a financial burden" as either of the 2 greatest difficulties, they were considered to have a financial burden for the purposes of this study.

We used several variables for descriptive purposes from the core BRFSS questionnaire. Caregiver demographic variables were: age (classified as 18-34, 35-54, 55-64, 65 or older), gender, marital status (married/coupled and unmarried), race/ethnicity (categorized as non-Hispanic white; non-Hispanic black; non-Hispanic Asian; non-Hispanic multiracial; and Hispanic any race; Other races), education status (less than high school, high school graduate, attended technical school or college, completed college or higher), employment (employed/homemaker/student, retired, not working/unemployed/unable to work), and annual household income level (less than \$15,000, \$15,000-24,999, \$25,000-34,999, \$35,000-49,999, \$50,000-74,999, \$75,000 or more, and missing). The following caregiver health status and behavioral predictors were examined: frequent mental distress; self-reported general health (dichotomized as excellent, very good, or good contrasted with fair or poor); disability (reporting either an activity limitation or use of special equipment [22]); body mass index (neither overweight nor obese [BMI < 25.0], overweight [BMI = 25.0-29.9], and obese [BMI ≥ 30.0]); ever being diagnosed with the chronic health conditions arthritis, asthma, diabetes (not including gestational and borderline diabetes), or heart disease; having had a stroke; smoking status (current, former, or never smoker); binge drinking status (men having 5 or more, women having 4 or more drinks on one occasion); pneumonia vaccination (ever or never for adults age 65 or older); and influenza vaccination (shot or spray in the previous 12 months). Frequent mental distress is an indicator of mental health defined as 14 days or more of poor mental health in the past 30 days is based on the question, "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past thirty days was your mental health not good?" [23].

Care recipient characteristics and aspects of the caregiving experience were also used to describe our population. Specifically, we considered the care recipient's gender, age (categorized as 0-5, 6-17, 18-34, 35-44, 45-54, 55-64, 65-74, 75-84, or 85 or older), and the major health problem that necessitated caregiving (as reported by the caregiver; responses included cancer, diabetes, dementia/Alzheimer's disease, arthritis/rheumatism, stroke, depression, heart disease, developmental delays, attention deficit disorder/attention hyperactive deficit disorder, cerebral palsy, anxiety or other emotional problem, asthma, and Down's syndrome). The relationship of the respondent (caregiver) to the care recipient (classified as parent, child, spouse, other family, and non-family) was assessed as well as the areas in which caregiving assistance was needed. Caregivers were asked, "Given this condition, with which TWO of the following areas does s/he most need your help?" Answer choices included learning, remembering and confusion; seeing or hearing; taking care of oneself, such as eating, dressing, bathing, or toileting (labeled self-care); communicating with others; moving around; getting along with people; and

feeling anxious or depressed. Caregivers reported the length of time they had been providing care (coded as 0-3 months, 4-12 months, 13-24 months, 25-60 months, 60 or more months), the average amount of time they provided care (coded as 0-8, 9-19, 20-39, and 40 or more hours per week), how far they lived from the care recipient (dichotomized to living in the same house or not), and whether they considered themselves the primary caregiver.

All analyses were completed in SAS version 9.2 [24]. SAS procedures, proc survey frequency and proc survey logistic, were used to account for the disproportionate stratified design the BRFSS employs and to calculate weighted results. From all variables used for the descriptive analyses, we chose several key ones for adjusted logistic regression models based on our expectations of factors related to financial burden from prior research and observed weighted estimates of association in our population. Caregiver age group, caregiver gender, caregiver employment status, annual household income, care recipient distance, hours per week of care, caregiver general health, and caregiver disability status were examined as predictors of financial burden. Resulting models provided an adjusted odds ratio (AOR) and 95% confidence intervals (95% CI) for associations between these factors and financial burden.

To test for differences across ordered categorical variables (age, income, and hours per week of care), logistic regression models were constructed taking into consideration the complex nature of the BRFSS survey design. The outcome was reporting a financial burden and each categorical item was included as the exposure variable, coded in one-point increments. For example, ages 18-34 were coded as "1," ages 35-54 were coded as "2," and so on. The Cochran-Armitage trend test [25] provides a global *p* value for the trend across ordered levels of a variable rather than individual *p* values for each level of the variable. This test does not assume that one point increments have any interpretational meaning, but only uses them to see if proportions are different across these increments. We generalized this method (the Cochran-Armitage trend test) for use with complex survey data [26].

Results

Of the total respondents in the 3 states, 8.4% (*n* = 3447) were caregivers. A total of 3,317 caregivers answered the question about difficulties associated with caregiving. Overall 12.5% of caregivers reported a financial burden (*n* = 414). Caregivers who reported a financial burden compared to those who did not were younger (overall mean age 44.8 years versus 49.0 years) and less likely to report the highest level of income (23.4% versus 31.7% reported earning \$75,000 or more per year) (Table 1). Caregivers who reported a financial burden were less likely to have frequent mental distress (67.5% versus 74.2%), more likely to report having had a stroke (3.7% versus 1.9%), and more likely to be current

Table 1

Weighted demographic and health behavior characteristics of caregivers as a function of reported financial burden in the states of Kansas, Hawaii, and Washington Behavioral Risk Factor Surveillance System (BRFSS), 2007

Variable	Financial Burden		p-value
	Yes (n = 414) 12.5%	No (n = 2,903) 87.5%	
	% or mean (95% confidence intervals)		
Age mean, y	44.8 (42.5, 47.2)	49.0 (48.1, 50.0)	<.0001 ^a
Age groups, y			.003 ^a
18-34	26.5 (19.1, 34.0)	20.4 (17.8, 23.0)	
35-54	46.2 (39.6, 52.7)	40.9 (38.5, 43.2)	
55-64	17.8 (13.8, 21.7)	22.1 (20.4, 23.8)	
65+	9.5 (6.7, 12.4)	16.6 (15.2, 18.1)	
Female	59.2 (52.5, 66.0)	58.5 (56.0, 61.1)	.85
Married or coupled	66.2 (59.6, 72.8)	67.9 (65.4, 70.4)	.64
White only, non-Hispanic	77.7 (72.1, 83.3)	76.7 (74.8, 78.7)	.78
Black only, non-Hispanic	2.2 (0.5, 4.0)	1.5 (0.9, 2.2)	.43
Asian only, non-Hispanic	4.0 (1.9, 6.1)	6.3 (5.2, 7.4)	.11
Multiracial	6.7 (3.9, 9.5)	8.2 (6.8, 9.5)	.40
Hispanic	3.8 (0.2, 7.4)	5.4 (4.1, 6.7)	.48
Other groups	5.0 (1.7, 8.3)	1.5 (0.9, 2.1)	.001 ^a
<High school	3.9 (1.0, 6.8)	5.6 (4.2, 6.9)	.27
High school graduate	27.9 (21.5, 34.4)	23.8 (21.6, 26.0)	
Technical school	35.0 (28.7, 41.4)	32.0 (29.7, 34.3)	
College or university	33.2 (27.2, 39.1)	38.6 (36.3, 40.9)	
Employed/homemaker/student	75.2 (69.7, 80.7)	72.9 (70.9, 74.9)	.46
Retired	10.7 (7.7, 13.7)	19.1 (17.6, 20.7)	<.0001 ^a
Not working/unemployed/unable to work	14.1 (9.2, 19.1)	8.0 (6.5, 9.5)	.005
Annual household income			.005 ^a
Less than \$15,000	6.8 (4.2, 9.5)	4.4 (3.4, 5.5)	
\$15,000-24,999	19.0 (12.9, 25.1)	11.4 (9.8, 13.0)	
\$25,000-34,999	11.7 (7.3, 16.1)	10.3 (8.8, 11.8)	
\$35,000-49,999	16.4 (11.8, 21.1)	14.9 (13.3, 16.7)	
\$50,000-74,999	16.8 (11.5, 22.2)	18.7 (16.8, 20.7)	
\$75,000 or more	23.4 (18.2, 28.7)	31.7 (29.5, 34.0)	
Missing	5.8 (3.3, 8.4)	8.3 (6.8, 9.8)	
Frequent mental distress ^b	17.5 (13.0, 22.1)	13.6 (11.7, 15.5)	.10
Fair/poor general health	15.3 (11.1, 19.4)	13.0 (11.3, 14.6)	.29
Disability status ^c	31.9 (26.1, 37.8)	26.0 (24.0, 28.1)	.05 ^a
Body mass index (BMI)			.19
Not overweight/obese (<25.0)	31.0 (25.2, 36.7)	36.6 (34.2, 39.0)	
Overweight (25.0-29.9)	37.8 (31.1, 44.5)	36.8 (34.4, 39.2)	
Obese (≥30.0)	31.3 (24.8, 37.7)	26.6 (24.4, 28.8)	
Ever had arthritis	33.1 (27.1, 39.1)	36.1 (33.8, 38.4)	.37
Ever had asthma	16.7 (12.4, 21.1)	16.6 (14.8, 18.4)	.94
Ever had diabetes	7.2 (4.7, 9.8)	8.9 (7.5, 10.2)	.27
Ever had heart disease	4.3 (2.4, 6.2)	3.3 (2.6, 4.0)	.30
Ever had stroke	3.7 (1.8, 5.5)	1.9 (1.4, 2.5)	.03 ^a
Currently smokes	30.2 (23.9, 36.4)	18.5 (16.5, 20.5)	.0001 ^a
Smoked in the past	23.5 (18.6, 28.4)	28.3 (26.2, 30.4)	.09
Never smoked	46.3 (39.6, 53.0)	53.1 (50.6, 55.6)	.06
Binge drinking ^d	12.3 (8.1, 16.5)	15.2 (13.2, 17.3)	.26
Pneumonia vaccine for adults aged 65+	56.3 (41.3, 71.3)	71.4 (67.4, 75.4)	.04 ^a
Influenza vaccination or spray	36.4 (30.4, 42.4)	42.8 (40.4, 45.2)	.06

^a Denotes significance at $p < .05$.

^b Defined as experiencing 14 or more days of poor mental health in the past 30 days.

^c Defined as either having an activity limitation or using of special equipment.

^d Men having 5 or more drinks on one occasion, women having 4 or more drinks on one occasion.

smokers (30.2% versus 18.5%) compared to caregivers who did not report a financial burden (Table 1).

Caregivers who reported a financial burden compared to those who did not more often provided care for younger recipients (18.0% versus 8.5% provided care for

recipients 18-34 years old, while 9.1% versus 20.5% provided care for recipients over 85 years of age), provided more hours of care in an average week (30.8% versus 21.6% provided 40+ hours of care per week), more often lived with the care recipient (50.7% versus 30.4%), and

Table 2

Weighted characteristics of care recipient and caregiving experience characteristics as a function of reported financial burden in the states of Kansas, Hawaii, and Washington Behavioral Risk Factor Surveillance System (BRFSS), 2007

Variable	Financial Burden		p-value
	Yes (n = 414) 12.5%	No (n = 2903) 87.5%	
	% or mean (95% confidence intervals)		
Female recipient	58.1 (51.4, 64.8)	62.8 (60.4, 65.3)	.18
Recipient age group, y			<.0001 ^a
0-5	3.2 (0.7, 5.7)	2.1 (1.0, 3.1)	
6-17	7.5 (3.8, 11.2)	4.6 (3.4, 5.8)	
18-34	18.0 (12.0, 23.9)	8.5 (6.9, 10.2)	
35-44	7.4 (4.2, 10.5)	5.3 (4.2, 6.4)	
45-54	11.5 (7.4, 15.7)	10.9 (9.0, 12.8)	
55-64	11.4 (7.4, 15.3)	10.4 (8.8, 11.9)	
65-74	12.3 (7.4, 17.2)	15.3 (13.6, 17.1)	
75-84	19.7 (14.3, 25.1)	22.5 (20.5, 24.5)	
85+	9.1 (6.1, 12.1)	20.5 (18.5, 22.3)	
Recipient health problem			
Cancer	10.3 (5.5, 15.1)	10.9 (9.4, 12.3)	.84
Diabetes	7.1 (2.0, 12.2)	5.5 (4.5, 6.6)	.50
Dementia/Alzheimer disease	9.0 (5.6, 12.3)	11.2 (9.7, 12.7)	.28
Arthritis/rheumatism	5.3 (2.4, 8.3)	4.3 (3.3, 5.3)	.50
Stroke	4.7 (2.2, 7.2)	5.0 (4.0, 6.0)	.80
Depression	4.3 (1.7, 6.8)	2.7 (2.0, 3.4)	.17
Heart disease	3.7 (1.9, 5.6)	6.9 (5.8, 8.0)	.02 ^a
Developmental delay	3.5 (0.8, 6.2)	2.4 (1.6, 3.2)	.40
ADD/ADHD	2.0 (0.2, 3.8)	0.9 (0.3, 1.4)	.12
Cerebral palsy	1.7 (0.3, 3.0)	0.8 (0.4, 1.2)	.15
Emotional problem	1.0 (0.2, 1.8)	1.5 (0.9, 2.1)	.35
Asthma	0.8 (0.0, 1.9)	0.4 (0.1, 0.7)	.34
Down syndrome	0.3 (0.0, 0.7)	0.6 (0.1, 1.1)	.31
Relationship to recipient			
Parent	25.4 (19.7, 31.0)	30.8 (28.5, 33.1)	.09
Child	16.2 (11.9, 20.5)	6.5 (5.4, 7.6)	<.0001 ^a
Spouse	18.4 (13.3, 23.5)	10.7 (9.3, 12.1)	.001 ^a
Other family	25.8 (19.5, 32.2)	29.5 (27.1, 31.8)	.31
Nonfamily	14.2 (9.3, 19.1)	22.5 (20.4, 24.6)	.008 ^a
Areas recipient needs most help ^b			
Learning/memory	22.0 (16.7, 27.4)	22.1 (19.9, 24.2)	.99
Seeing or hearing	3.4 (0.9, 6.1)	7.0 (5.7, 8.3)	.07
Self-care	41.2 (34.2, 48.1)	35.7 (33.2, 38.2)	.15
Communicating with others	12.4 (8.4, 16.4)	10.6 (9.0, 12.2)	.38
Moving around	39.4 (32.5, 46.4)	40.8 (38.3, 43.4)	.72
Getting along with people	6.0 (3.3, 8.8)	6.5 (5.2, 7.9)	.75
Anxious/depressed	30.5 (23.9, 37.1)	22.6 (20.5, 24.7)	.02 ^a
Length of care			.20
0-3 months	20.9 (15.0, 26.7)	22.9 (20.7, 25.0)	
4-12 months	21.7 (15.9, 27.4)	23.2 (21.0, 25.5)	
13-24 months	15.7 (10.6, 20.8)	13.8 (12.2, 15.4)	
25-60 months	16.4 (12.0, 20.9)	20.8 (18.8, 22.8)	
60+ months	25.2 (19.6, 30.9)	19.3 (17.5, 21.1)	
Hours per week of care			<.0001 ^a
0-8 hours	33.9 (27.4, 40.4)	50.8 (48.2, 53.5)	
9-19 hours	14.8 (9.1, 20.4)	14.2 (12.3, 16.0)	
20-39 hours	20.5 (14.9, 26.2)	13.4 (11.7, 15.2)	
40+ hours	30.8 (24.4, 37.2)	21.6 (19.4, 23.7)	
Co-residence	50.7 (44.0, 57.4)	30.4 (28.1, 32.7)	<.0001 ^a
Primary caregiver	53.8 (47.1, 60.5)	35.4 (33.2, 37.8)	<.0001 ^a
Greatest difficulty faced by caregiver ^b			
Not enough time for caregiver	16.3 (11.6, 20.9)	16.9 (15.1, 18.7)	.81
Not enough time for family	7.9 (4.9, 10.9)	12.6 (10.9, 14.2)	.19

(Continued)

Table 2
Continued

Variable	Financial Burden		<i>p</i> -value
	Yes (n = 414) 12.5%	No (n = 2903) 87.5%	
	% or mean (95% confidence intervals)		
Interferes with work	11.9 (6.7, 17.1)	10.6 (9.0, 12.3)	.59
Creates/aggravates health problems	2.7 (1.2, 4.1)	4.2 (3.3, 5.1)	.11
Affects family relationships	5.3 (3.0, 7.6)	9.9 (8.4, 11.5)	.05 ^a
Creates stress	35.3 (29.0, 41.5)	40.9 (38.4, 43.4)	.11

^a Denotes significance at $p < .05$.

^b Percentages reflect how many within the columns selected each option as one of their 2 areas that care recipient need help with or difficulties faced by respondent; those who did not select the option comprise the rest of the 100%.

were more frequently the primary caregiver (53.8% versus 35.4%) (Table 2).

Associations between financial burden and demographic, caregiving situation, and health status characteristics are displayed in Table 3. The univariate model was adjusted for caregiver age, gender, income, care recipient residence, hours per week of care, general health of caregiver, and caregiver disability status to obtain the adjusted odds ratios (AOR). Younger caregivers (ages 18-34) had significantly higher odds of reporting a financial burden compared to caregivers age 65 and older (AOR = 2.66, CI: 1.55, 4.56) and a significant trend, as demonstrated by our variation of the Cochran-Armitage test, existed between age and financial burden ($p < .0001$). Caregivers who lived with the care recipient were more likely to report a financial burden (AOR = 2.25, CI: 1.61, 3.13). Odds of having a financial burden were higher for caregivers who spent between 20-39 hours per week providing care compared to caregivers who typically provided 0-8 hours of care per week (AOR = 1.67, CI: 1.09, 2.56). The trend, according to the Cochran-Armitage test, was not significant across hours of care per week ($p = 0.06$). Caregivers with a disability were more likely to report a financial burden than were caregivers without a disability (AOR = 1.54, CI: 1.10, 2.16). There was no significant relationship between income and financial burden within any one category, but the trend test revealed a relationship between these variables ($p = 0.02$; as income increased financial burden decreased).

Discussion

In our study involving over 3,400 randomly sampled respondents who identified themselves as informal caregivers, nearly 13% reported experiencing a financial burden due to caregiving. The NAC/AARP study, which examined caregivers who provided care to persons with at least one or more limitations in daily activities, found 38% of the respondents reported experiencing a financial burden [2]. Our study respondents were asked to identify the 2 areas in which they experienced the most difficulty related to caregiving, whereas the NAC/AARP study asked

respondents to report financial hardship on a scale of 1 (no hardship) to 5 (a great deal of hardship). Thus, if we examine those in the NAC/AARP study who reported scores of 4 and 5 on the financial hardship scale (i.e., great burden), we found that 12% of their respondents reported high levels of financial hardship, which is comparable to our study.

Our results show that younger caregivers (age group 18-34 years old) experience greater financial burden than

Table 3
Binomial and adjusted logistic regressions of financial burden and co-factors of interest, Kansas, Hawaii, and Washington Behavioral Risk Factor Surveillance System (BRFSS), 2007 (N = 3,317)

Variable	Crude odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Caregiver age group (<i>p</i> for trend ^a < .0001)		
18-34	2.27 (1.38, 3.73)	2.66 (1.55, 4.56)
35-54	1.97 (1.37, 2.82)	2.31 (1.52, 3.50)
55-64	1.40 (0.95, 2.07)	1.60 (1.02, 2.49)
65+	1.0 (referent)	1.0
Female	1.03 (0.77, 1.39)	0.96 (0.70, 1.31)
Male	1.0	1.0
Annual Income (<i>p</i> for trend ^a = .02)		
< \$15,000	2.07 (1.21, 3.54)	1.72 (0.92, 3.19)
\$15,000-24,999	2.25 (1.39, 3.64)	1.72 (0.99, 3.00)
\$25,000-34,999	1.53 (0.92, 2.53)	1.62 (0.96, 2.72)
\$35,000-49,999	1.49 (0.98, 2.26)	1.37 (0.86, 2.17)
\$50,000-74,999	1.22 (0.77, 1.92)	1.15 (0.72, 1.85)
\$75,000 or more	1.0	1.0
Missing	0.95 (0.55, 1.65)	1.02 (0.54, 1.93)
Care recipient residence		
Same house as caregiver	2.35 (1.76, 3.15)	2.25 (1.61, 3.13)
Different house	1.0	1.0
Hours per week of care (<i>p</i> for trend ^a = .06)		
0-8 hours	1.0	1.0
9-19 hours	1.57 (0.94, 2.60)	1.31 (0.82, 2.09)
20-39 hours	2.29 (1.51, 3.47)	1.67 (1.09, 2.56)
40+ hours	2.14 (1.49, 3.08)	1.35 (0.90, 2.03)
General health		
Excellent/very good/good	1.0	1.0
Fair/ poor	1.21 (0.85, 1.73)	0.91 (0.59, 1.41)
Has a disability	1.33 (1.00, 1.78)	1.54 (1.10, 2.16)
Does not have a disability	1.0	1.0

^a The *p* value for trend tests the null hypothesis that there is no relationship with the outcome across ordinal categories of the exposure.

older caregivers. Younger adults tended to have less established financial lives and careers, which may limit their available income and younger adults also may have a more difficult time managing available income. Studies have shown that younger adults who are caregivers reported having less time for themselves and experience problems in the workplace and in relationships including marriage [27]. However, the number of studies about financial resources and caregiving are somewhat limited in this age group.

Caregivers who reside with the care recipient were found to have greater odds of reporting a financial burden. The relationship between co-residence and burden persisted even after adjusting for annual household income. In fact, annual household income was only marginally significant suggesting that co-residence itself was the strongest predictor of financial hardship among these caregivers. One possible explanation is that the extent of needed care requires a person to reside with the recipient, thus inhibiting the caregiver from working or requiring them to pay for certain services.

Caregivers who provided 20-39 hours of care per week more frequently reported a financial burden, although there was no statistically significant difference across the categories of hours of care when it was included as an ordered categorical variable. One interpretation is that caregivers who reported 40 or more hours of care per week also resided with the care recipient. The inclusion of the co-residence variable in the model with hours of care adjusts for that factor and makes this category no longer statistically significant. Even though co-residence may have confounded results for that category of hours of care per week, it has a strong relationship with financial burden, independent of the inclusion of hours of care per week; therefore, we kept it in our final model. Differentiating components of the extent care should be examined in other studies to see if tasks, time, or a combination thereof are related to financial stress.

Our study indicated an association between financial burden and caregivers who have a disability. Few studies have investigated caregiving among people who have a disability, particularly as related to financial burden. Thus, additional work is needed to better understand this relationship. Governmental programs are in place that aid persons with disabilities who are unable to work [1]; however, these results indicate that those who provide care for someone else with a disability either need additional financial assistance or may not be receiving any.

Unlike previous studies, gender [28] and income [2] did not significantly impact the likelihood of reporting a financial burden after adjusting for the control variables. A recent meta-analysis found that some gender differences in the caregiving experience do exist, but are very small in magnitude. In general, there are more similarities than differences between male and female caregivers [29]. Income itself may not play a role in perceived financial burden, but as our results indicate, caregiver age and personal caregiving

situation (i.e. living conditions, disability status, and hours of caregiving) are better predictors of reporting a financial burden than income.

The present study has several limitations. The cross-sectional survey design of the BRFSS leads to concern about temporal sequence; thus, we cannot determine whether being an informal caregiver caused a financial burden or if having underlying financial problems resulted in being more likely to take on the role of caregiver. It is plausible that individuals who cannot afford to pay for a formal caregiver for their family member because of unemployment or low income take on the caregiving role; in these cases, financial constraints would cause informal caregiving rather than informal caregiving causing a financial burden. Similarly, we cannot make any assumptions about whether the reported financial burden was due to a loss of income due to caregiving as we do not have information about previous household income. This is an area that should be further explored. We also cannot assume that caregivers who do not report having a financial burden as one of their top 2 choices truly do not have financial difficulties. However, our interest is in perceived significant financial burden, which would induce the caregiver to seek out services. The Caregiving Module was only administered in the 3 states of Hawaii, Kansas, and Washington; therefore, we are limited in the ability to generalize our results to the entire nation. The BRFSS has a population-based design and is weighted to account for sampling issues and non-response; thus, despite its limitations findings can be generalized to caregivers in the 3 states, and may offer some idea of the risk for financial burden in other parts of the U.S. Starting in 2009, the Caregiver module became available to all states and territories as an optional module. As more states elect to use this module, future research can be conducted to further describe the financial burden associated with caregiving in the United States and to identify factors that cause this burden.

Existing evidence shows that financial support programs for informal caregivers significantly impact their levels of burden. Cash & Counseling, which is available in King County, Washington, is an evidence-based program that aids Medicaid recipients in obtaining more options for at-home care to best meet their needs [30]. A study done in the 3 original Cash & Counseling states (Florida, Arkansas, and New Jersey) found that informal caregivers of children and elders enrolled in the program reported better outcomes and lower financial strain than those using Medicaid alone [31].

Such programs are not available nationwide and additional interventions are necessary to support informal caregivers. In a 2008 report, Thomson Reuters (formerly Medstat) ranked states' Medicaid spending in terms of how much is spent on home and community-based versus institutional long-term services for fiscal year 2007 [32]. Washington ranked at number 6 and Kansas at number 9. Hawaii ranked much lower at number 24; however it does provide Kupuna Care, a statewide, state-sponsored program

designed to meet the needs of older adults who cannot live at home without adequate help from family and or formal services [33]. Although these rankings indicate that respondents from 2 of our states have substantially more financial resources available to them than the rest of the nation, our study shows that financial burden is a problem in all 3 states. This may indicate that services are either not accessed or are insufficient, a gap that needs to be addressed.

Other types of resources are available throughout the nation. The National Institutes of Health funded Resources for Enhancing Alzheimer's Caregiver Health (REACH), which identified a multifaceted intervention for caregivers that resulted in significant improvements in their quality of life and depression [34]. There have been several state-based demonstration projects implementing the REACH intervention. The Alabama REACH intervention proved that the REACH intervention can be modified for feasible and effective use in Area Agencies on Aging (AAA) [35]. Several refinements to further improve program quality and impact have been incorporated into the design of the condensed community-based model, officially named REACH OUT (Offering Useful Treatments). This model continues to be implemented in Alabama and was recently initiated in North Carolina. Nationally, the National Family Caregiver Support Program (NFCSP) provides grants to states to fund support programs such as individual counseling, information and access to services, and respite care based on the state's proportion of the population 70 years and older [36].

States provide limited aid to children with disabilities through Medicaid. As our research shows, younger caregivers and those with disabilities tend to experience more financial stress than older caregivers. Programs aimed toward younger caregivers, such as spouses of people with disabilities, as well as additional aid for caregivers with disabilities should be developed because, as Talley and Crews described, the population of caregivers is broad and complex [1]. The increasing numbers and needs of caregivers necessitate that the public health system works with caregiver networks and devote more attention to caregiving.

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